

**Virginia Genetics Advisory Committee
Tuesday, March 29, 2005
10:00 a.m. – 12:00 Noon**

**Division of Consolidated Laboratory Services
Room T-23
600 North 5th Street
Richmond, VA 23219
Telephone (804) 648-4480**

MINUTES

Members: Willie C. Andrews—DCLS; Lynette Bartlett, RN—VDH; Joann N. Bodurtha, MD, MPH, Chair—VCU; Mary Ann Discenza—DMHMRSAS; Laura Duncan, MPH, RD—VCU; Nancy Ford, MPH, RN—VDH; Kathy Orchen—VDH; Arti Pandya, MD, MBA—VCU Virginia (“Ginny”) K. Proud, MD—CHKD; Jene O. Radcliffe-Shipman—VDH; Raphael Randolph—VDH; Ether Richardson, LPN—VDH; Ramona Schaeffer—VDH; Charlie Stevenson, MS—DCLS; David Suttle, MD—VDH; Sharon Williams, MS, RN—VDH; William (“Bill”) G. Wilson, MD—UVA Health Sciences Center; Melody Persinger Yeargin—CHKD

Guests: Tyler Cox and Katie Webb (for Susan Ward, HHCA); Valerie Luther, Vicky Hardy-Morrell, Alice Schaeffer, Cliff Schroeder

Recorder: Nancy Ford

Time	Item	Person	Notes/Plan
10:00 to 10:15	1. Welcome a. Introductions b. Approval of 10/5/04 Minutes c. Review of Agenda d. Membership	a. J. Bodurtha b. J. Bodurtha c. J. Bodurtha d. N. Ford	a. Completed. b. Approved as written. Note: Final minutes are posted on the VDH Minutes Calendars Web site: http://www.vdh.state.va.us/minutes/minutes.asp c. No new items. d. Circulated for corrections.
10:15 to 10:45	2. Updates: Agencies, Organizations, Grants a. VDH: Virginia Genetics Program, including VNSS legislation. b. Division of Consolidated Laboratory Services (DCLS) c. VDH: VaCATPIP I, VaCATPIP II, EHDI grants. d. VDH: Virginia Sickle Cell Awareness Program e. VCU: March of Dimes Grant “Genetic Services and Education-Assessment of Needs” f. March of Dimes, Va. Council on Folic Acid g. DMHMRSAS: Part C of	a. S. Williams b. J. Pearson, W. Andrews c. N. Ford d. J. Shipman e. J. Bodurtha f. S. Long g. Mary Ann Discenza h. G. Smith	a. HB 1824 and SB 1184 reviewed. Expanded newborn screening panel will go into effect March 1, 2006. VDH and DCLS working on emergency regulations and implementation plan. Lynette Barlett is the new Newborn Screening Nurse Sr. b. Multiple inspections completed, including today’s CLIA visit. DCLS agency-wide information management system under development. c. CDC-funded VaCATPIP I 3-year grant ended 2/1/05. VaCATPIP II 5-year grant awarded and began 3/1/05. CDC 3-year EHDI grant application submitted; if awarded will begin 7/1/05. d. Starting to introduce follow up for those identified with sickle cell trait. Family needs assessment tool being evaluated by parents. Multiple professional and community education activities

	IDEA: Infant & Toddler Connection of Virginia h. Dept. of Education		<p>highlighted.</p> <p>e. Year 1, 2, and 3 assessment activities summarized. Members generated suggestions for year-3 key stakeholders survey participants. Proposed survey questions will be sent to members for review and comments.</p> <p>f. Folic acid PSA, which features Lisa Collis, was broadcast 2/1/05-3/13/05. Folic acid supplements were purchased and will be distributed to targeted populations via VDH Family Planning clinics.</p> <p>g. Collaborating with VDH on implementing automatic/semi-automatic referrals to early intervention via Virginia Infant Screening and Infant Tracking System (VISITS). Collaborating with DOE and VDH on USDOE grant to develop early intervention outcomes and track health indicators.</p> <p>h. No report.</p>
10:45 to 11:00	3. Updates: Virginia Genetic Centers a. EVMS b. UVA c. VCU d. Genetics and IVF Institute	a. J. Bodurtha b. V. Proud c. B. Wilson d. H. Stern	<p>a. Completed first year of contract with VDH to provide metabolic treatment center services. Genetic staffing stable.</p> <p>b. At full capacity with genetic counselors.</p> <p>c. Recruiting for new dean. Need to address funding and Hispanic language and cultural issues.</p> <p>d. No report. Focus is on prenatal genetic services (no pediatric genetic services).</p>
11:00 to 11:10	4. Review/Update: VaGAC Infrastructure, including membership	J. Bodurtha with group discussion	Brief history provided. No changes made to infrastructure. Subcommittees urged to continue to recruit new members (e.g., certified nurse midwives, genetic counselors) to participate as needed, including more diversity.
11:10 to 11:50	5. Subcommittee/ Work Group Reports a. Newborn Screening /Tandem Mass Spectrometry b. Parent Involvement c. State Genetics Plan d. VDH Contractors	a. W. Andrews b. A. Schreiber c. J. Bodurtha d. S. Williams	<p>a. Assistance provided to VDH and Joint Commission on Health Care for Newborn Screening Study, which was presented to 2005 General Assembly (HJR 164). Working with VDH on implementing HB 1824 and SB 1184, funding will be via increases collection kit fee. Five infants diagnosed with MCAD via Virginia Newborn Screening Services, since MCAD became a mandated screen.</p> <p>b. Continues to evolve. Guests who are parents of children with genetic conditions provided suggestions on improving services (e.g., importance of educating parents and follow up).</p> <p>c. Will become more active after Genetics Needs Assessment completed (see 2e).</p> <p>d. Conference call will be set up to discuss</p>

			combining genetic centers and metabolic treatment centers contracts and reporting requirements, which will change.
11:50 to 11:55	6. New Business	a. All	a. Members discussed system challenges related to expanded newborn screening panel, including follow-up services, funding issues, and evidence-based protocols for physicians. b. Dr. Pearson came by to welcome members and express regret at not being able to attend today's meeting.
11:55	7. Next Meeting	J. Bodurtha	Next Meeting: Date: Tuesday, October 4, 2005 Time: 10 a.m. – 12 p.m. Location: DCLS
12:00	8. Adjourn	J. Bodurtha	Meeting adjourned at 12 p.m. ^{1, 2}

¹ The Steering Committee met at 12:05 p.m. and scheduled their next audio-conference call for Thursday, September 22, 2005, 2 p.m.

² The Newborn Screening Subcommittee met at 12:15 p.m.